

Posttraumatic Stress and Psychological Growth in Children With Cancer: Has the Traumatic Impact of Cancer Been Overestimated?

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ABSTRACT

Purpose

To examine posttraumatic stress disorder and posttraumatic stress symptoms (PTSD/PTSS) in children with cancer using methods that minimize focusing effects and allow for direct comparison to peers without a history of cancer.

Patients and Methods

Children with cancer ($n = 255$) stratified by time since diagnosis, and demographically matched peers ($n = 101$) were assessed for PTSD using structured diagnostic interviews by both child and parent reports, and survey measures of PTSS and psychological benefit/growth by child report.

Results

Cancer was identified as a traumatic event by 52.6% of children with cancer, declining to 23.8% in those ≥ 5 years from diagnosis. By diagnostic interview, 0.4% of children with cancer met criteria for current PTSD, and 2.8% met lifetime criteria by self-report. By parent report, 1.6% of children with cancer met current criteria and 5.9% met lifetime criteria for PTSD. These rates did not differ from controls (all P s $> .1$). PTSS levels were descriptively lower in children with cancer but did not differ from controls when all were referring to their most traumatic event ($P = .067$). However, when referring specifically to cancer-related events, PTSS in the cancer group were significantly lower than in controls ($P = .002$). In contrast, perceived growth was significantly higher in the cancer group when referring to cancer ($P < .001$).

Conclusion

These findings suggest no evidence of increased PTSD or PTSS in youths with cancer. Although childhood cancer remains a significant and challenging event, these findings highlight the capacity of children to adjust, and even thrive, in the face of such challenge.

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INTRODUCTION

For more than a decade, posttraumatic stress disorder and related symptoms (PTSD/PTSS) have been a dominant psychological outcome studied in both adults and children with cancer, as well as in parents of children with cancer.¹⁻⁴ In pediatric settings, PTSD appears particularly widespread, with estimated lifetime prevalence of cancer-related PTSD ranging from 20% to 35% in survivors, and 27% to 54% in their parents.³ We suggest that these estimates are significantly overstated. On the basis of the assumption that cancer is a traumatic event, most studies examining PTSD/PTSS in childhood cancer patients have used designs that create "focusing" effects⁵⁻⁷ and lack control comparisons,^{1,3,4} factors that have biased the literature toward pathologic outcomes.

A "focusing illusion" occurs when people are cued to a specific factor (eg, cancer) before reflecting on an internal state.⁵ They are then prone to exaggerate the importance of that factor on their functioning, which influences their reports of their psychological state. The effects can be dramatic.⁵⁻⁷ Studies of PTSD in the cancer setting typically assume cancer as a *Diagnostic and Statistical Manual of Mental Disorders—Fourth Edition (DSM-IV)*⁸ A-criteria event and orient respondents to cancer when completing questionnaires. This primes the respondent to think of his or her cancer experience as traumatic and may have a significant impact on subjective reports. One study that did not orient respondents to cancer found that $\leq 10\%$ of childhood cancer survivors spontaneously identified their cancer as a traumatic event.⁹

Another consequence of designs focused on cancer as trauma is that it is difficult to identify appropriate comparisons. As a result, most studies simply omit them.¹⁻⁴ This approach assumes that all symptoms reported are a direct result of cancer, ignoring the background level of symptoms normally occurring in any sample. However, the symptom criteria that define PTSD are nonspecific, overlapping with other mood and anxiety disorders, or common distress associated with nontraumatic life stress.¹⁰ Thus, PTSS will be commonly reported by many, regardless of past trauma history, and controlling for this is essential.

But even if the diagnosis of cancer was experienced as a traumatic event, the assumption that this would be associated with pathology is not empirically supported. Approximately two thirds of children experience at least one traumatic event by age 16, yet PTSD is rare in children, with an estimated prevalence of less than 1%.¹¹⁻¹³ Current research suggests most individuals respond to stressful events with minimal lasting impact on functioning, and with a relatively stable trajectory of adjustment.¹⁴ Many individuals exposed to traumatic events may also experience positive effects, commonly referred to as posttraumatic growth, and these have been documented across numerous trauma, particularly medical illness.¹⁵⁻¹⁷

We examined PTSD/PTSS and psychological growth in a pediatric cancer sample using methods designed to avoid focusing effects while still allowing for a cancer-specific assessment, and controlling for significant, non-cancer-related events, with an appropriate comparison group. We hypothesized that (1) the majority of children with cancer would not spontaneously identify cancer as a traumatic event; (2) rates of PTSD and PTSS would not differ between children with cancer and healthy peers; and (3) rates of growth and/or perceived benefit will be greater in children with cancer, particularly when referring to cancer-related events.

PATIENTS AND METHODS

Participants

Patient group. Participants were treated at St Jude Children's Research Hospital (Memphis, TN). Eligibility criteria included (1) age 8 to 17 years, (2) diagnosis of malignancy, (3) ≥ 1 month from diagnosis, (4) English-speaking, and (5) no significant cognitive or sensory deficits. Patients were recruited in four strata based on time elapsed since diagnosis (1 to 6 months; > 6 months to 1.99 years; 2 to 4.99 years; ≥ 5 years). Of 378 children approached, 258 (68%) agreed to participate. Participants and nonparticipants did not differ by age, sex, race/ethnicity, or cancer diagnosis. Three provided incomplete data, leaving 255 evaluable patients.

Control group. Comparison participants' eligibility included (1) age 8 to 17, (2) no history of serious illness, (3) English-speaking, and (4) no significant cognitive or sensory deficits. Children were recruited from regional schools. Permission slips distributed through the schools included demographic information, and the returned data were used to create a pool of potential participants, who were subsequently contacted on the basis of demographic match. Of 107 who were contacted, 101 (94%) agreed to participate.

Measures

Clinician-Administered PTSD Scale for Children and Adolescents (CAPS-CA).¹⁸ This structured interview assessing DSM-IV PTSD criteria in youth provides both current and lifetime diagnoses of PTSD. Questions are based on the event identified by the child as their most traumatic. It is widely used for assessing PTSD in children.¹⁹ Using six raters, average absolute agreement across nine inter-rater dyads was 98% for current PTSD (average $\kappa = 0.85$), and 98% for lifetime PTSD (average $\kappa = 0.91$). Interviews were administered separately to both the child and participating parent.

University of California, Los Angeles PTSD Reaction Index for DSM-IV (PTSDI). This 22-item questionnaire assesses PTSS.^{20,21} Respondents describe their most traumatic event and respond to questions in relation to that event. In the current study, reliability (Cronbach's α) for the total score was .89.

Benefit Finding/Burden Scale for Children (BFBS-C). This 20-item questionnaire assesses perceptions of benefit and burden associated with a specified event.^{22,23} We report only on perceived benefit, used as a measure of psychological growth. Internal reliability (α) was .90. Participants completed the PTSDI first and completed the BFBS-C in reference to the same event identified on the PTSDI.

Life Events Scale (LES). This 30-item measure²⁴ is a modification of the Coddington Life Events Questionnaire.²⁵ It includes both A1 events and others that do not meet A1 criteria but are expected to have a significant stressful impact (eg, parental divorce). Children indicate whether they have experienced each event, and when it occurred. We have demonstrated that stressful life events remain a salient correlate of PTSS after controlling for demographic and medical factors.²⁶

Procedure

After providing informed consent and assent, children and parents completed survey questionnaires. Participants spontaneously identified their most stressful or traumatic life event without preemptive orientation to cancer. Diagnostic interviews for PTSD were based on their self-identified event. It was not required that the chosen event meet DSM-IV A1 criteria, as A-criteria events have not been clearly established as a necessary condition for PTSS,¹⁰ and non-A1 events often result in equal or greater symptom severity,^{27,28} particularly in children.^{29,30} However, we also compared outcomes on the basis of A1 versus non-A1 events. Three diagnostic interviews were conducted: one with the child reporting on their own PTSD symptom history, and two with the parents, reporting on their child's symptoms and their own. This report focuses on child outcomes. When interviews were completed, patients in the cancer group who did not identify a cancer-related event as their most traumatic were asked to complete the PTSS and perceived benefit/growth questionnaires again, specifically in relation to their cancer experience. This ensured that groups could be equivalently compared on the basis of what they spontaneously identified as their most traumatic event, and also allowed for a cancer-specific assessment for all patients without a preemptive focusing on cancer, or suggestion that the cancer experience was traumatic.

Statistical Analyses. Four outcomes were examined: (1) The percentage of cancer patients who spontaneously identified a cancer-related event as their most traumatic. (2) Comparison of rates of full PTSD (current and lifetime) in cancer and healthy controls based on diagnostic interview, by child and parent reports. Our sample of 255 patients and 101 controls provided 80% power to detect a between-group difference of 5% based on Fisher's exact test, assuming very low rates (ie, approaching 0%) of PTSD. (3) Between-group comparisons of child-reported PTSS. Cancer-group PTSS were examined in three ways: (a) PTSS reported from the spontaneously identified most traumatic event, regardless of whether it was cancer-related; (b) cancer-related PTSS; and (c) PTSS for noncancer events. These events were further differentiated by whether or not they met A1 criteria. All cancer-related events were considered as having met A1. Group comparisons were conducted with linear regression controlling for differences in socioeconomic status (SES) and life events. The sample size provided 80% power to detect a group difference of 0.33 SD, or approximately 5 points on the University of California, Los Angeles measure. (4) Self-reports of perceived benefit were examined in the same manner as for PTSS. The study sample provided 80% power to detect a group difference of 3 points or greater on the BFBS-C. A *P* value of .05 was used to define statistical significance.

RESULTS

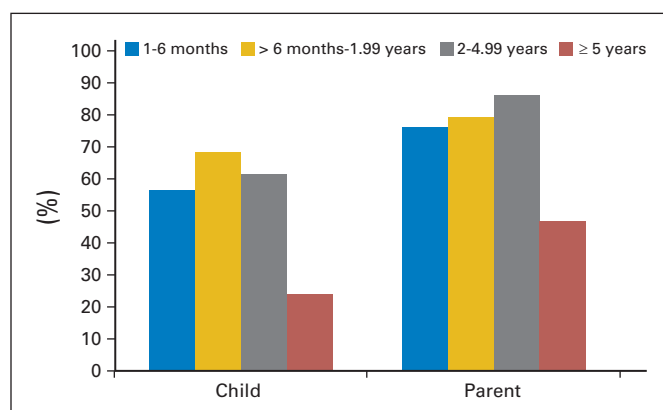
Participant Characteristics

Demographic and medical factors are summarized in Table 1. Patient and comparison groups did not differ on any demographic

Table 1. Demographic and Medical Background Characteristics of Participants

Characteristic	Cancer		Control	
	No.	%	No.	%
Age, years				
Mean	12.7		12.1	
SD	2.9		2.9	
Male sex	132	51.8	57	56.4
Race				
White	185	72.5	73	72.3
Black	58	22.7	24	23.8
Other	12	4.7	4	3.9
Socioeconomic status				
Groups I & II	70	27.5	50	49.5
Group III	81	31.8	29	28.7
Groups IV & V	103	40.4	22	21.7
Parent participant				
Mother	212	83.1	90	89.1
Father	31	12.2	11	10.9
Other	12	4.7	0	0
Diagnostic category				
ALL	61	23.9		
Other leukemia	18	6.3		
HD/NHL	34	13.3		
Solid tumor	98	38.4		
Brain tumor	44	17.3		
Time since diagnosis				
Strata 1: < 6 months	64	25.1		
Strata 2: 6 months to 1.99 years	63	24.7		
Strata 3: 2 to 4.99 years	65	25.1		
Strata 4: > 5 years	63	24.7		
Time since chosen stressful event				
Past year	97	38.7	42	43.3
1-2 years	34	13.6	14	14.4
2-5 years	62	24.7	19	19.6
> 5 years	58	23.1	22	22.7

Abbreviations: ALL, acute lymphocytic leukemia; HD/NHL, Hodgkin disease/non-Hodgkin lymphoma; SD, standard deviation.

**Fig 1.** Differences in proportion endorsing the child's cancer as most traumatic event by time elapsed since diagnosis, by patient report and parent report.

not significantly different from the 39.0% of control parents who did so ($P = .08$).

Rates of current and lifetime PTSD. Child diagnostic interview on the CAPS-CA identified one child (0.4%) who met current criteria for full PTSD in the cancer group. This case resulted from a noncancer event, a drive-by shooting in which the child was injured and his cousin was killed. For lifetime PTSD, seven children (2.8%) in the cancer group met criteria. Of these, two were cancer related. The noncancer events included the drive-by shooting, displacement by Hurricane Katrina, becoming homeless, and two unexpected deaths of family members. There were no cases of current or lifetime PTSD found in the control group, but the groups did not differ significantly (Fisher's exact test, $P = .9$ for current; $P = .2$ lifetime).

On the basis of parental interview, four children met current criteria for PTSD, all in the cancer group, a rate of 1.6%, which did not differ significantly from controls ($P = .6$). Of these cases, two were identified by parents as resulting from cancer-related trauma. In the cancer group, 15 children (5.9%) met criteria for lifetime PTSD. Control parents reported two children (2.0%) as meeting lifetime PTSD criteria, again not significantly different from the cancer group ($P = .17$).

Cancer-Control Comparisons

On the LES, children with cancer reported significantly more stressful events (mean = 7.6; SD = 3.5) than did controls [mean = 6.7; SD = 3.0; $t(353) = 2.25$; $P < .05$]. Because history of a serious illness is an included event for all in the cancer group but not for controls, this approximate 1-point difference is expected and suggests a comparable frequency of noncancer events between groups. The LES score was included as a covariate in all subsequent comparisons.

Cancer group PTSS means are reported separately for (1) the most traumatic event, regardless of relation to cancer; (2) cancer-related PTSS; and (3) PTSS when referring to a noncancer event. Further, for all participants, PTSS means are reported by whether the event met A1 criteria (Table 2). Youths with cancer did not differ from their peers when reporting on their most traumatic event ($P = .067$). However, when referring to cancer-related events, PTSS was significantly lower in the cancer group ($P = .002$). When A1 criteria were met, the cancer-control differences were magnified, highlighting lower scores in the cancer group ($P < .001$). In all comparisons, life

factors, with the exception of SES, [$\chi^2(df = 4) = 19.1$; $P < .01$], where there were fewer low-SES children, and more high-SES children in the control group.

Identification of cancer as traumatic event. Within the cancer group, 52.6% of patients ($n = 134$) identified a cancer-related event as their most traumatic. This rate did not differ by demographic factors or diagnostic category. However, it differed significantly by time elapsed since diagnosis (Fig 1). Patients in strata 1 to 3 (< 5 years from diagnosis) identified cancer as their most traumatic event more than 50% of the time, whereas those in strata 4 (≥ 5 years from diagnosis) did so only 23.8% [$\chi^2(df = 3) = 29.5$; $P < .001$]. Similarly, parent report differed by time since diagnosis; more than 75% in strata 1 to 3 identified cancer as their child's most traumatic event, declining to 47.6% in those whose child was ≥ 5 years from diagnosis ($P < .001$; Fig 1).

For patients who did not identify their cancer as a traumatic event ($n = 121$), 57.6% reported noncancer events that met DSM-IV A criteria, a rate not significantly different from the 51.5% in the control group ($P = .4$). For parents who did not identify their child's cancer as traumatic ($n = 60$), 50.7% reported other events meeting A criteria,

Table 2. Cancer and Control Group Differences in PTSS and Perceived Benefit

Measure	Cancer			Control			<i>P</i>	Cohen's <i>d</i>
	No.	Mean	SD	No.	Mean	SD		
PTSS								
Identified event								
Most stressful event	245	18.0	13.6	96	19.7	15.8	.067	−0.118
Cancer event*	240	15.5	12.7	96			.002	−0.304
Noncancer event*	116	19.0	13.6	96			.343	−0.047
Does identified event meet A1 criteria?								
Yes								
Most stressful event	196	17.9	13.4	47	22.1	16.2	.006	−0.301
Cancer event*	240	15.5	12.7	47			< .001	−0.492
Noncancer event*	67	19.4	13.2	47			.072	−0.187
No								
Noncancer event	49	18.4	14.2	49	17.4	15.2	.658	0.074
Perceived benefit								
Identified event								
Most stressful event	243	29.2	10.5	99	25.9	9.4	.045	0.317
Cancer event*	245	31.6	10.7	99			< .001	0.551
Noncancer event*	111	24.8	9.7	99			.072	−0.122
Does identified event meet A1 criteria?								
Yes								
Most stressful event	195	30.8	10.3	49	28.6	9.7	.484	0.218
Cancer event*	245	31.6	10.7	49			.203	0.290
Noncancer event*	63	26.4	10.1	49			.014	−0.218
No								
Noncancer event	48	22.6	8.7	50	23.3	8.5	.738	−0.089

NOTE. Cohen's *d* is effect size.

Abbreviation: SD, standard deviation.

**P* values refer to tests comparing the cancer group to controls, after controlling for differences in SES and life events. Cancer group means are presented based on type of event referenced, compared with the entire control sample. For comparisons differentiated by whether A1 criteria were met, control means are also presented separately for those who did and did not report events meeting A1.

events score was a significant covariate (all *P*s < .001), indicating greater PTSS associated with more frequent life events. For perceived benefit, those in the cancer group reported significantly higher levels, except when referring to a noncancer event (*P* = .072, Table 2). It is notable that self-reports of both PTSS and benefit/growth were nearly identical across groups when the youths with cancer referenced noncancer events. In contrast, group differences were greatest when refer-

encing cancer, but in opposite directions, with lower PTSS (*P* = .002) and greater perceived benefit (*P* < .001; Fig 2).

DISCUSSION

We examined PTSD/PTSS and perceived benefit in a large cohort of children with cancer and comparison children using psychometrically

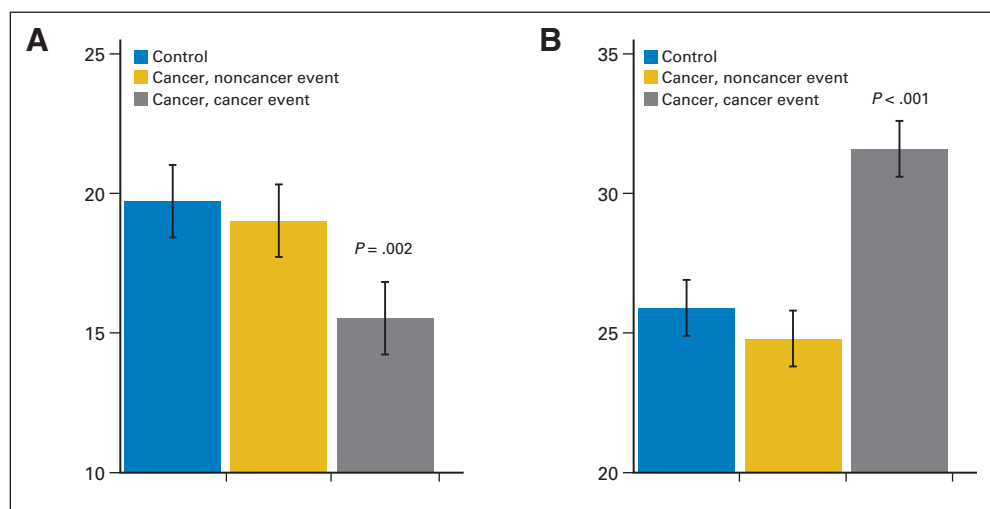


Fig 2. Self-reported levels of (A) post-traumatic stress symptoms (PTSS) and (B) perceived benefit in patient and control groups. Patient reports are presented separately for cancer-related and noncancer-related events. *P* values refer to the comparison of cancer-related reports to control reports for (A) PTSS and (B) perceived benefit.

robust measures, reports from both children and caregivers, and a methodology that minimized focusing effects. The findings indicate a prevalence of current PTSD of 0.4% and a lifetime prevalence of 2.8% in youths with cancer by self-report. These rates are comparable to those reported in community samples of children,¹¹⁻¹³ suggesting that the experience of childhood cancer does not substantially elevate the risk of PTSD. It is noteworthy that most (five of seven) PTSD cases were linked to traumatic events other than cancer. Rates of current and lifetime PTSD were slightly higher by parent report, but not significantly different from those of controls. Approximately half of the patient sample, and less than a quarter of long-term survivors, referenced cancer as their most traumatic event.

These findings contrast with much of the prior literature, which has characterized the traumatic effects of pediatric cancer as a common problem.³ Our results are likely reflective of three methodological distinctions: (1) We made efforts to reduce focusing effects by avoiding an initial orientation to cancer, or suggestion for patients to think of their cancer as traumatic. We submit that this has contributed to overestimation of PTSD/PTSS in prior studies. (2) We included a reasonably matched comparison group and used an identical approach to assessment in both patients and controls. (3) We used a structured diagnostic interview, considered the gold standard for diagnosis of PTSD,¹⁰ but rarely used in prior pediatric psycho-oncology research. There is evidence to suggest that questionnaires may substantially overestimate PTSD relative to a diagnostic interview.^{32,33} For example, a recent study of Iraqi war veterans reported a PTSD rate of 21% using survey questionnaires, but this declined to a rate of 4% when based on diagnostic interview.³³

Our findings also provide no evidence of elevation in PTSS in youths with cancer in comparison to community peers. This is consistent with the few prior studies that have included controls.³⁴⁻³⁷ Limiting the comparison to only those controls who report on an event meeting A1 criteria further magnifies the lower scores in the cancer group. An unexpected finding was the lower level of PTSS within the cancer group when referring to cancer versus noncancer events. This highlights the importance of avoiding focusing effects. In the absence of any suggestion for patients to think of their cancer as traumatic, they are far less likely to report symptoms.

Why has posttraumatic stress been such a focus of pediatric psycho-oncology research? The initial inclusion of PTSD in the *DSM-III* was intended to address unusual and pervasive traumas, as might be experienced in wartime. Successive revisions of the *DSM* expanded the definition of criterion A to include the experience of life-threatening illness.¹⁰ One of the first articles to address this in children with cancer suggested, without empiric evidence, that PTSD “occurred almost without exception in this population.”³⁸ This stimulated research designed with an expectation of high rates of PTSD. But when the estimated rate of PTSD in military personnel deployed to Iraq and Afghanistan is only 4.3% (1.4% in noncombatants),³² expecting much higher rates of PTSD in the contemporary setting of pediatric oncology appears unwarranted. We suggest that much of the research in this area simply reflects “accurate measures of the prevailing bias,”^{39(p700)} and that

the problem of PTSD in childhood cancer is an example of a “perpetuated fallacy.”^{40(p645)}

Some limitations of the study must be considered. This is a single-site study, which may constrain generalizability of the findings. However, we have participated in prior multisite studies using similar outcome measures, in which no site differences were detected, suggesting the current findings are not unique to our setting.⁴¹⁻⁴³ Our comparison group was not fully matched on SES and life events, potential correlates of PTSD. This was mitigated statistically, and correcting for SES and life events served to strengthen the findings. Finally, given the relatively low (68%) participation rate of patients, it is possible that patients who declined participation were more psychologically distressed. However, our single-center design allowed for complete ascertainment of the rates of clinical referral for psychological services as a result of adjustment problems in both participants (33%) and nonparticipants (39%), which was not significantly different.

The low levels of PTSD/PTSS observed should not be taken as evidence that the experience of cancer in childhood is not a highly significant and challenging event. Rather, this serves as another example of the human capacity to thrive in the face of even the most difficult life challenges.⁴⁴ Research across diverse potentially traumatic events has demonstrated that such resilience is the modal outcome, and this may be particularly true in children.^{14,44,45} Beyond resilience, there is evidence that potentially traumatic events may promote benefits, or psychological growth.¹⁵⁻¹⁷ Resilience is defined as a positive psychological outcome (ie, minimal distress and disruption in function) despite exposure to adverse experiences or potentially traumatic events.^{14,44} In contrast, growth refers to positive change experienced as a result of the struggle with trauma, often manifest as closer social connections, enhanced empathy, increased emotional strength, and so on.^{15-17,46} The current data provide evidence of both resilience and growth in relation to the cancer experience. Not only do children with cancer report low levels of PTSS (resilience), but they also report higher levels of perceived benefit (growth) than do their peers, and the perception of benefit is greater for cancer-related than non-cancer-related stressors. There may be unique elements of the childhood cancer experience that contribute to these outcomes, but to the extent that the diagnosis and treatment of cancer provide an exemplar of randomly occurring childhood adversity, the capacity of children to adjust, and even thrive, in the face of major life challenges should not be underestimated.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

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Manuscript writing: All authors

Final approval of manuscript: All authors

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